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ABSTRACT

This report documents the personal views and experiences gained while conducting training courses for caregivers of persons with mental handicap in many countries of Asia. The experiences are presented as an example of what can be done in a situation of limited material resources to improve the lives of people with mental handicap in developing countries. The training approach considers the cultural context of people of Asia, the terminology used for "mental handicap," and the need to have a caring attitude towards individuals with mental handicap. The educational program offered to caregivers is designed to combat negative social attitudes towards individuals with disabilities. The program uses informal gatherings, home groups, and simplified presentations, avoiding school-like sessions. Low-cost materials are used. Topics covered include: the physical, spiritual, and mental needs of the person involved, as well as his/her parents, teachers, and society; educational principles; cleanliness; intellectual disciplines; parent-teacher relations; skills for living; sex education; ethical issues; physical education; natural massage; and first aid. Indications are noted that some Asian nations are establishing an institutional or structured approach to the education and care of persons with intellectual handicaps. (JDD)

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Training of Persons who Care for Persons with Mental Handicap

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An Asian Experience

Fr. Adam B. Gudalefsky
Sr. Ching Madduma

1992

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International League of Societies
for Persons with Mental Handicap

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A Document
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A Foreword by the President of the ILSMH

All human beings have the same basic rights, including education, care and training. The majority of the world's population, however, benefit very little from these rights. I am speaking about the people who are living in developing countries. The most deprived among them are the persons with handicaps - in particular people with mental handicaps.

Even today more than 90% of the worldwide expenditures on rehabilitation of the handicapped is being spent in the industrialized countries, whereas more than 70% of all disabled persons are living in developing countries.

I have to admit that also in the ILSMH the interests of industrialized countries are often dominating. The topics of conferences or papers too often focus on their needs, in spite of the fact that the majority of the League's member societies are from developing countries.

Therefore the ILSMH and its Committee on Mobilization of Ressources (MORE) has started a movement on "MORE Action for Development". The basic intention is to motivate all the committees and functional organs of the League to deal with development-related issues.

As one of the first activities, I have asked for good examples which are relevant for the vast number of persons with mental handicap and their families in developing countries.

Our friends, Fr. Adam Gudalefsky and Sr. Ching Madduma, have agreed to share with us the important personal views and experiences they have gained while conducting training courses for "persons who care for persons with mental handicap" in many countries of Asia. I am sure that this is a good example of what can be done in a situation of limited material ressources, but with dedicated parents and staff members.

I sincerely hope that community- and family-oriented approaches like this will develop to a large extend during this decade. All of you have the opportunity to contribute to this development, thus helping to improve the lives of persons with mental handicap in developing countries.

Victor Wahlström, President

INTRODUCTION

One word that would sum up the experience of living, for over twelve years, in the snowlands of Hokkaido - Japan's northernmost island - is the word "exhilarating". Not only was the climate exhilarating, but much more so was the challenge to reach out to service persons with special educational needs. During the years on that island near Siberia, the Oriental culture curtain parted and revealed a shadow world of intense drama: the real lives as lived by persons with mental handicap.

The curtain, veiling the shadowy world of these people in need, opened more widely during six years work on special educational efforts at the "other end" of Asia - in the Himalayan Kingdom of Nepal. The contrasts of these two different worlds (Japan and Nepal) were most striking. They are dissimilar not so much in regard to scenery or climate, but very different in the prevailing attitudes of people, in the qualities of life, in the processes of social services, in the total tapestry of the care, rehabilitation and education of persons with learning difficulties.

Nevertheless, the many continental and island countries in Asia are now, in reality, parts of the global village. Advances in travel, in communications are bringing the people of these nations, and of the world, to interact more closely with one another. We now live in a multi-cultural milieu. Our individual designs for living affect each other. Cultural values have become intertwined, and must be respected and appreciated if education is to have a proper framework of reference, and so that it can be presented in a way that will be effective.

We, Fr. Adam Gudalefsky and Sr. Ching Madduma, have had many learning experiences, pioneered various educational experiments, and spent much time reflecting on matters related to the care and services for persons with mental handicap not only in Nepal and Japan, but also in the cultural contexts of some twenty-six countries of Asia, the South Pacific and Africa. This knowledge, derived from actual participation in the multi-varied cultures, has prompted us to formulate a simple, adaptable, and replicative personal-family-based educational approach to better the care and development processes for people with learning difficulties. This approach is basically what the late Professor Alan Roeher spoke about at a Conference in 1982. He identified it as a "mass manpower model" to reach out to the unreached masses of persons with mental handicap.

Simply stated, this approach intends to cope with the "mass problems" resulting from the increasing number of persons with mental handicap in the world today by means of a "mass service group" - self, family and community involvement in the responsibility of bettering the quality of life of people with mental handicap.

Our educational programs (about 130 sessions conducted in the past 12 years) present the basics of education and a methodology of education that is non-institutional, non-professional, and low in cost factor. The second objective of our programs is an informational-based social educational process for the person, the family, the community in regard to matters related to special education and/or mental handicap.

We have had in our courses as participants several thousand people - persons with mental handicap, parents, teachers, non-professional and professional persons; the rich and the poor; the learned and the unlearned. Through our association and common efforts with these people of many countries, the cultural curtains of many Asian countries have opened wider, thus enabling us to appreciate and respect more fully the circumstances relative to the particular values, beliefs, and practices associated with people with special educational needs (in Japan, Taiwan, China, Hong Kong, Macau, Philippines, Indonesia, Vietnam, Thailand, Bangladesh, Nepal, India, Sri Lanka, Malaysia, Pakistan, Cook Islands, Tonga Republic, Western Samora, Fiji, the Solomon Islands, Canuatu, Nigeria, Ethiopia, Uganda, Zimbabwe, Mauritius, and Papua New Guinea). These words are our personal reflections about the "scene" - the life situations as they exist today for persons with mental handicap.

CULTURAL CONTEXT

The fascinating cultures of people of Asia present a unique mosaic of behavioral developments in languages, communications, diet, settlements, individuation, social stratification, mobility, interpersonal relations, religious beliefs and practices, life-cycles, education and death. These factors identify Asia as "Asia". It is in the framework of an individual culture - the encompassing of all patterns of human behaviour - that opinions are formed, and social attitudes are shaped concerning all matters which local people consider as being "social acceptable conduct" or "social problems". It is consequential, then, that in all cultures, persons who are regarded as "deviants" from social norms and expectations are given the least in preference and privileges due.

But first of all, the human elements of love and dedication to people in need are no less in Oriental countries and among Asian people than in other places in this world. There is a deep sincerity, goodness, and concern which characterize the hearts of Asian people. Joys and hurts are felt by each person in these respected countries. Birth and life bring joy; suffering and death bring sorrow to each person. So, too, with the coming of mental or physical handicaps into one's life, or into family life, there is pain. There is suffering that only can be assuaged with understanding, love and compassion. All Asian cultures do have a vibrant nucleus of caring people. All people - be they literate or illiterate - are generally enthusiastic to learn what they can do, or what can be done to care for persons with special needs. Mixed motivations do exist. Nevertheless, many good people are trying, with the best of their own energies, knowledge and available time and resources to assist in education and care for persons with mental handicap.

Generally, cultures and social developmental trends in one country often seem to follow the same pattern or to resemble cultures and social development trends existing in another country (particularly in East and West comparisons). However, it is important to note that cultural circumstances which are comprehended by "outsiders" are often far from the true life conditions as comprehended by the culture's "insiders". Therefore, it must be admitted in honesty and in justice that the observations and comments of this paper are those of "outsiders", and these thoughts are generalities derived from our own personal life experiences during the years we have lived and worked in Asia. We are resigned to the fact that "outsiders" will never be able to have a full view of the whole real world existing in Asia.

Terminology

A realistic appreciation of the "problem of people with mental handicap" in Asiatic countries does not begin with a head count of the number of people estimated or classified to be in this controversial category. Nor can valid conclusions be achieved merely by knowing the statistics concerning institutions, service personnel, financial commitments, or the like. Complacency with these calculations - that they are the true picture of educational development - is simply to accede to the "numbers game".

An honest understanding of the problem must begin with an honest appreciation of the use of proper language (terminology, vocabulary, formulation of concepts, emotional connotations, etc.). In most countries of Asia, the use of words or the use of

character-writing are grossly inadequate, incorrect, and prejudicial when applied to persons with mental handicap (as well as persons with physical disabilities). Many Asian languages have as their "roots", or are dependent upon, Chinese written characters. In this type of calligraphy, the formation and the interpretation of mental concepts are focused particularly on the use of the eye, that is, the sense of seeing. In the case of persons with mental handicap, then, the identifying words (the character "picturing the person" and written about the person as seen) may vary from "blessed" in one culture, to "crazy", "possessed", "diseased", in other cultures. In general, the people of Asia have widely-accepted notions that mental (and physical) handicaps are to be attributed to magic, to sorcery and/or to religious experiences. The severity of the handicap is often thought to be befitting the persons according to the extent of their own, or their parents' "sins committed". Local solutions (this involves the entire field of folk healing) and therapy practiced on persons labelled as handicapped may vary from over-compensating benevolence to tragic abuse, including death.

The problem of language is not only characteristic of Eastern countries. It exists in the Western world as well. This is evident by the continuous language search and research being done by societies and agencies dedicated to work and to serve persons having intellectual disabilities. The International League of Societies For Persons With Mental Handicap and Rehabilitation International are two groups attempting to refine language usage and terminology as applied to persons with mental handicap. They propose to formulate a more realistic language in the field of special education, and to alert people to use a proper and a non-prejudicial vocabulary. "Labelling" is a term gradually fading from use in lectures, conferences, and writings related to persons considered to be intellectually handicapped.

It was shocking and unacceptable to many delegates at a recent world conference to hear a European representative state (unabashedly) that his country "has solved the problem of defectives" by the introduction of widespread amnio-centesis and other pre-natal testing procedures. Surely, in the audience, there were many people who well-remembered the statement made by Adolf Hitler (in the mid-1930s), when he had massacred most of the mentally and physically handicapped persons in Germany. He said then: "We have gotten rid of the defectives in our land." Realistically, how far have we advanced in our efforts in the past 50 years? At the same conference, a person with mental handicap responded when asked the question: "What should we ("normal people") call you?" His answer - startling and thought-provoking - was: "Call me Mister!"

Today, cultural circumstances in Asian countries remain rather rudimentary in regard to language related to mental handicap, handicaps, disabilities, etc. Persons with special needs, their parents/guardians all have high hopes that an acceptable and non-demeaning terminology will develop soon. Unfortunately, in several (many) Eastern countries, special educational and financial means and ways remain inaccessible to the majority of people in need at "grassroots" levels for the persons and the families. These local people could, if properly instructed and encouraged, formulate appropriate vocabularies, present proper concepts and attitudes, develop meaningful terminologies and symbols related to matters of mental (and physical) handicaps. In all Asian publications (public and private), there is an urgent need to establish a positive, non-biased and rational vocabulary relevant to understanding disabilities, handicaps, learning difficulties in the context of individual cultures.

Persons who care

There does exist, in all countries of Asia, a dedicated core group of people who are interested and involved in advocating the cause of persons with mental handicap. However, in the majority of places, it is usually the "professional groups" (people in medicine, in psychiatry, in psychology; on occasion a person in health or education) who have initiated care and rehabilitation services. And these persons or groups have rarely given up control of the movements or the functioning organizations in their respective cultures. The professional groups or persons remain today the so-called "decision-makers", the "pace-setters" in formulating the language used and the actions taken in regard to persons with mental handicap.

We present here some findings in our research work (done in Nepal and Macau) concerning mental handicap, and from our evaluations collected from our program participants in twenty-six countries. The conclusions of these studies indicate that the local professional people themselves often are not only negative in their attitudes and in the care of persons with educational needs, but also this respected group is often the source of improper terminology. Some reasons for this situation in Asian countries are:

1) Some professional people here do not have any, or a proper, background for work in the field of special education.
2) Some professionals, who do have a "bit of book knowledge" in the service of handicapped (and disabled) people, do not have sufficient practical experience to benefit the client.

3) Many professionals fail to adapt their knowledge, which is usually Western-orientated, to local cultural concepts.
4) Not a few professional people look to personal gain (in social standing or financial). The place and the role of professional people and groups in the education, care and service of persons with mental handicap in Asian nations remain very sensitive issues today. (A senior official in a major government here in Asia told us: "Your Western professionals come to our country and look down their noses at our professionals, who look down their noses at our people. We do not want this type of help.")

Today there is an urgent need for people of the Western world to look seriously at the cultural traditions and options of action that many Asian cultures offer. They continue to emphasize the harmonious relations among body, mind and spirit in educating and caring for all persons. Reciprocal exchange is essential in this developmental effort.

During the past several decades, as part of the continuing effect of colonial and neo-colonial heritages, it has become the accepted role of many professionals in developing countries in Asia to follow Western services models. In their efforts to adapt Western technology, they have come to ignore the fact that large buildings, sizeable staffs, and costly institutionalization do not equate to productive special educational services. A service system, in order to be effective, must be acceptable by ordinary local users. Therefore, in mimicking others, professionals have often produced counter-cultural results: special education facilities which are out of place and out of proportion with local economies, the lack of proper support systems, communication problems, etc. One answer to this aberration is that the under-rated "mass" of parents, teachers, volunteers must be welcomed and informed to make a more effective and culturally acceptable response to special educational needs in Asia. The ordinary people must be made socially aware that they have the competence to educate and to care for persons with mental handicap in their homes, in their communities. History has shown well that real progress has not been made by sole reliance on the expertise of "professionals". Guidance, counselling, moral and social support - these can instill confidence and ecourage parents and volunteers to reach out to help persons with intellectual handicaps in all places.

THE STAGE

In the late 1960s, I (Fr. Adam) was the supervisor of a small day-care center for children who were "slow". The school, with 30 students and 11 staff members, was located in northern Japan. Our institution was one of over 2,600 establishments in the whole of Japan that were care-givers for people with special educational needs. Because of the availability of government funds, which seemed almost unlimited, it was the "fashion" in those days to build institutions for the people in need. Our center was small, almost insignificant in comparison with "entire villages" and "large centers" (some having the capacity of several hundred to one thousand "community members") built "to take care of a problem". We heard it said: "This is the way it is done in the West." And this became the way it was done in the East. The "Big-is-Beautiful" idea seemed to answer the educational and rehabilitation needs. Living standards, educational qualifications, financial and personal expenditures - all of these factors, if "BIG", then they meant "BETTER". They removed persons with physical and mental handicap from their natural and normal home and community lives into a separate world of "institutions". Some Asian pioneers in this educational service field felt secure in imitating the "advanced" Western world. The end result is that most Asian nations have gotten into the same rut, and continue to prolong activities long-proven socially and ethically questionable in servicing persons with mental handicap. Basically, the stage for programs in the field of mental handicap in Asia is about the same (with very slight differences) as that which existed in Europe decades ago.

It is true that the past thirty years have brought great political and financial changes to most nations. National budgeting for social welfare and for educational purposes in many places has fluctuated extremely. In some countries, new educational procedures have resulted in an exodus of people out of institutions, and have revealed the many flaws in institutional life. Many facilities in the Western world have closed their doors. A small number of Asian countries have also closed institutions. Large, custodial institutions throughout the world have tended to dehumanize the people who entered them. But still, most nations in the Orient rate their progress in servicing persons with mental handicap by the number of institutions built each year. Everywhere the pressing demand for more and more funding is never ending.

In too many Asian institutions - which were originally intended for severely and profoundly handicapped persons - most places are now occupied by people who are slow learners, or those with handicaps which are not severe. Rooms

and places for persons who are severely handicapped or with compound disabilities are very limited in numbers, and, as a result, most of these people are left to fend for themselves at home, or are abandoned, or relegated to a place of confinement for people who are mentally ill. Among Asian people there exists a compulsion ("a cultural trait") to continue constructing large-sized physical plants/structures. It seems that such costly establishments are meant to give visual evidence that the problem of caring for persons with special needs is fully recognized and cared for by the responsible authorities.

There is a need for the existence of proper institutions and for centers to care for people with severe mental handicap in countries of Asia. However, a practical rationale of the purposes and proper objectives of these institutions or care centers is absolutely necessary before committing personnel and finances. The establishment of educational, care and rehabilitation facilities must be within the framework (cultural, social and economical) of the prevailing circumstances of the country. Lessons should be learned from history. The services provided by these institutions and hospitals must be directed entirely to the care of profoundly handicapped persons.

But these institutions must not become "dumping grounds", places of confinement where severely and multiple handicapped people are "committed", and parents/-guardians never visit afterwards. Some parents desert their sons and daughters and go off to other countries, never intending to return. They argue: "I do pay the institution people each month for care services. Why should I visit?" In addition, some care-givers see their work only as a job, and thus little educational or rehabilitation services are offered.

Again, in order to promote more tourism in some countries, governments pass laws "to rid the streets of street-sleepers, who are considered mentally handicapped". Some laws permit committing "those arrested" to institutions. In Asia, the percentage of people who certainly need institutional care is small (but increasing). These people are not to be neglected, and should be given appropriate priority when applying for services at care facilities. In Asia, there are too many facilities for mentally ill persons that are populated with persons who have, or who aresuspected of having a mental handicap. There are also "forgotten" places - formerly prisons or jails of a sort - occupied by hundreds of persons who were "arrested" because they are handicapped or "looked like they were mad." Legal sanctions which are grossly unjust in regard to people with mental handicaps must be considered as critical ethical

issues today. The rights and the responsibilities of parents/guardians, of local and state government officials associated with institutional services must be much more clearly articulated in most Asian countries.

A variety of political systems and structures do exist in the countries of Asia. Because of the varied political systems and governmental organizations, it is often difficult to find out who is in charge when it comes to services for persons with special educational needs. This clouded circumstance leads to adverse complications and frustrations for the person, the family, the advocates in matters of authoritative decisions, disbursement of funds, law-making, etc. In some countries of Asia, accountability rests with the Ministry of Education (where it seems proper that the major responsibility should be); in other countries, it is with the Department of Social Welfare (if it exists); in some nations, the Department of Civil Affairs is the in-charge group. There are other countries where care of persons with mental handicap is placed with a Committee or Foundation functioning under the patronage of royalty or titled nobility. Non-government agencies have extensive authority in some places. Where state governments have not done serious planning, or because of the lack of interest, grave organizational and financial consequences in social service and educational service programs have materialized.

During the International Year of the Child (1979), during the International Year of Disabled Persons (1981), and during the Decade of Disabled Persons (1983 - 1992), many positive and constructive programs were begun and successfully completed in Asian countries. Today, many dedicated people still continue to contribute much time and great efforts to advance the cause of persons with intellectual handicaps. However, in some places, this expenditure of physical and mental energies in the service of persons with mental handicap is being rendered not as a service due, nor as an exercise of professional expertise, nor even as charitable work, rather, what is done is done as a means of personal (status or financial) gain. In several countries of Asia, stagnation of interest in the "problem" and the slow progress of care-giving services has led to much disillusionment and frustration for people involved. There are very few ideas as to what do we do now?

Asia is a fantastically vast area. It contains over half of the world's population. Asia has the largest number of handicapped and disabled persons. Asia and its multi-cultured people have been neglected in this field of special education too long, not only by local authorities, but also by international agencies. For all intents and purposes, in regard to mental handicap, Asia remains in a "World of Shadows".

THE BACKGROUND

Ignorance breeds contempt in many Asian countries. And ignorance concerning primary causes, the proper care, and human values in regard to persons with mental handicap is extremely rampant in the cultures of Asia. Here it is rare to find or publicly see mentally handicapped persons. Many have died because of lack of proper care. Others have been eliminated. During our extensive travels to Asian countries, we have rarely been introduced to or have established contact with persons with profound mental handicap. And, when we have met such persons, we have found out that most of them had become intellectually and/or physically handicapped after birth: because of accidents, diseases, malnutrition, environmental reasons, etc. Research findings indicate that specific localities in Asia have a significant number of persons who are intellectually handicapped. Other communities have large numbers who are physically handicapped. Persons who are severely or multiple handicapped are "seldom seen" in public. In certain areas, the causes of these large concentrations of people with handicaps and/or disabilities seem to be: endemic goiter, consanguinity problems, epidemics, and environmental reasons. The greater number of these people in critical need of services remains unknown and without care today. Prevention and early intervention programs are pathetically few or non-existing. Human rights are concepts which are hard to find in some cultures of Asia.

The acceptance of persons with mental handicap as equals in all Asian societies is often limited by very basic barriers. Survival issues, inheritance issues, financial issues of grave proportions are "pressures" involved in fashioning the lives of all members of societies on this side of the globe. No less for persons with intellectual handicaps. These serious problems are too often "solved" flippantly by persons whose intentions dictate that people with mental handicap should be excluded from full participation in local community life. The "weaker elements" of society (of the community) are meant to receive only "affordable charity", pity, and scorn.

Some Asian nations are beginning to admit they have "problems" in the care of their citizens who happen to be "slow". They say that Western influences have misled them to build inappropriate and costly large institutions. They say there is a lack of employment opportunities and social prospects for persons who are handicapped. They also say that the struggle for personal monetary gains, the development of an "elitist professionalism", and the like deter them from properly giving service to people with special educational needs. Mixed motivations, ambivalences, and confusion of sorts are characteristic of the Asian movements in the care and the

education of persons who are intellectually handicapped. Yet, still today, countries here (government and non-government agencies) continue to imitate the ways of developed nations. Other Asian people bitterly oppose anything "Western". The realistic situation of persons with mental handicap in Asian countries is that they are generally considered useless, a burden, a "problem" ... their existence is hardly recognized and more often ignored. In countries where this group of citizens is accepted, very often it is a case of more and more being done for fewer and fewer who need less and less.

PERFORMANCE

What is being done or what can be done in an Asian context with so many varied cultures and people involved, and with so many people with special needs? What options exist to better the whole person, physically, spiritually, and mentally?

Recognition must be given to the world-wide and local movements initiated during the International Year of the Child, the International Year of Disabled Persons, and the Decade of Disabled Persons. Resource and informational materials are now readily available in more places and in more languages in Asia. The trickle of relevant data into all levels of societies is helping to better public attitudes about children and family members who are mentally handicapped. There is belated cooperation of mass media groups. There is enactment of some civil laws. There is more meaningful budgeting of government finances in rare places. However, these are not sufficient to cope with the problems existing, and growing.

A "mass" of people (volunteers, non-professionals and professionals) is needed to respond to these problems, to get involved in a personal way, to be dedicated to the "cause" of servicing people with special educational needs in their homes, in communities, in nations. This "mass" of people should have some basic knowledge (common sense), education, training in the care of persons with mental handicap. For Asia, we have initiated a viable educational program proceeding from "bottom to up" structuring ... "grassroots" ... rather than from "top to down" present-day focus. Rather than being "community-based", these programs are more personal (the person who is intellectually handicapped) and family-centered or -based. We explain our optional program in the following. It is an option of service that has proven to be viable, effective, and self-replicative in Asia, in Africa and in South Pacific areas.

Educational Programs

"An Educational Program For People Who Care For Persons With Mental Handicap" is the title of the presentation. Over the years and based upon the suggestions made by the thousands of participants in their written evaluations of the programs, we have improved the contents, added new topics, and adapted presentations to rural, urban, developed and non-developed societies. The primary objectives of the program are:

1) To give to all interested and dedicated people some basic education concerning awareness, methodology and educational processes concerning the care of persons who are mentally handicapped (so these persons can live a normal human and social life).

2) To contribute, in a positive and effective way, programs of social awareness and education concerning matters pertaining to mental handicap.

For people to be participants in our educational program, we have two requisites only:

1) All participants must have a love for persons with mental handicap.

2) All participants must be dedicated to help persons who are mentally handicapped.

We are not interested in the participant's social, educational, or economic status. If any of the two requisites are lacking, we do not accept the candidate. This screening is meant to save our time, the candidate's time, and the time of persons with mental handicap. In this option, we stress that responsibility for a person'sdesign for living is primarily with the person herself, with the parents/guardians, and with the local community members.

Small groups of participants are scheduled for lecture periods, and attendance and participation in demonstration classes. Our expectation is that the program will be self-replicative ("Trainees becoming trainers"). The use of non-structured groupings (that is, informal gatherings, home groups, meetings on verandas, under a tree, etc.) simplifies presentations, and avoids school-like sessions. The persons with special needs, the parents, the volunteers themselves confidently conduct the roles normally monopolized by professional people.

The use of low-cost materials (local appropriate teaching materials which are items normally used in daily living, the use of indigenous medicines, traditional arts, crafts, skill, etc.) as a mode of cultural respect and of self-reliance capitalizes on the creativity and imagination of the participants in the programs. This method of operation negates the prevalent idea that much money and many specialized skills are needed in order to succeed in educating persons with mental handicap for daily living and self-independency.

The educational programs are based on the principle that "Small is beautiful." There are no aspirations on our part (or on the part of the participants, we hope) of establishing a "big business", or becoming an "employment agency", or being a means of certification in "specialist training". Smallness is ideal to nurture confidence, solidarity in purpose; and it allows for greater flexibility and adaptability to rural and urban situations. Usually there are about fifteen participants, although we have had as few as four and as many as one hundred and fifty people for sessions. This method of presentation also informs the participants that they, too, can conduct similar programs and not be burdened with concerns about high costs, the presence of foreign experts, the expertise of specialists, the necessity of large (and well-equipped) buildings. Education and care rightfully begin where they should: in the home and with the family.

The educational programs generally consist of a six-days period of time. There are forty hours of presentations: 20 hours of lectures, and 20 hours of class demonstrations. The daily schedule of the program requires the participants to spend seven hours each day in study and work. Five or six students, who may have any level of disability, take part in the demonstration class sessions and are present for about four hours each day.

Lecture and demonstration topics are as follows:

- The Purposes and Aims of the Program; An Explanation of Mental handicap and Learning Difficulties.
- The Physical, Spiritual, Mental Needs of the Person, of Parents, of Teachers, and of Society.
- Educational Principles, Process, and the Use of Class Outlines.
- Rationale of Scheduling; and the Use of Written Records.
- Concerning Research.
- Concerning Case Histories.
- Concerning Toiletry, Cleanliness and Discipline.
- Concerning Intellectual Disciplines (Words-Numbers-Communications).

- Concerning Physical Disciplines and Dental Hygiene.
- Concerning Parents'-Teachers' Relations; Home Visitations; Volunteer Services.
- Concerning Multi-Sensory Educational Materials (Demonstration).
- Concerning Skills For Living (Demonstration).
- Concerning Human Personality and Sex Education.
- Concerning Ethical Issues and Persons With Mental handicap.
- Concerning Physical Education, Games and Sports (Demonstration).
- Concerning Natural Massage (Demonstration).
- Concerning First Aid and Natural Medicines.
- Class Outline Presentations by Participants.
- Class Demonstrations by Participants.

The lecture periods are given from forty-five minutes to one hour in duration, and these are given at various times during the daily schedule. Home assignments are given to the participants on three occasions. (For persons who cannot write, we ask the cooperation of others to help.) Upon the successful completion of the program, a Certificate of Achievement is given to each participant. There are no fees received from the participants, nor are there any stipends given to the participants for this educational program. The program presenters work as volunteers and do not receive any recompense for their efforts or expertise. Lecture and class notes (about 200 pages) have been translated into several languages and are usually distributed during the sessions. The written materials* are periodically updated. An evaluation in writing is received from each participant concerning the program, its presentation and contents.

These programs are fulfilling an important service - soliciting a "mass" response - in many countries of Asia. The programs are simple, comprehensive and understandable. They are adaptable to different places, numbers, circumstances. They are in conformity with stated objectives and priorities to utilize an extensive manpower force - preferably on a voluntary basis - to educate and care for the unreached millions of normal persons who happen to be "slow" in Asia. The programs have been self-replicative at the "grassroots" level. They have been an excellent channel for basic and concrete expressions of our human love and compassion - here and now - for persons who are intellectually handicapped.

*This material is available from the author

Using the Media

Social awareness concerning mental handicap is a key factor in our planning. Informational-based (utilizing all forms of mass media) programs are rare in Asia. Here we touch upon an on-going experiment in India. This program is meant to be a "model" for possible use in other areas of Asia.

The objectives, goals, and targets of the community-based awareness program in India are calculated to inform and to educate women in particular (mothers, and those who will be mothers one day) in matters pertaining to basic health care, physical and mental disabilities and handicaps, and rehabilitation procedures. Local available mass media avenues and personal contacts are the channels for the informational process.

This particular program focuses on mental handicap. It was begun in the Varanasi District of northern India, in 1990. The program uses the local radio station (estimated listening audience is five to ten millions.), the printed word (books, pamphlets, newspapers - in the local languages), and discussion periods in the villages to achieve its aims. The facilitator conducts a number of programs in special education in this area. She states: "All people can do something to help, if they are aware of the need."

The awareness program capitalizes on mass communications

- to inform
- to educate
- to change attitudes
- to initiate prevention procedures
- to rehabilitate and humanly develop persons with mental handicap
- to accomplish these objectives in a low-cost manner.

The program also includes helpful information related to health practices, literacy, family support, etc. Normally there are six village groups (20 - 25 members; ages from 12 years old and up) meeting each week. The meeting places used to be in individual homes; however, recently one-room "information centers" are established. At the "center" are a variety of newspapers, books and pamphlets. The pamphlets distributed have come to be in this manner. A local person writes a story based upon a topic from the books: Where There Is No Doctor and Disabled Village Children.* Both books are authored by David Werner, and printed by Hesperian Foundation, California. These

*Hesperian Foundation, P.O. Box 1692, Palo Alto, CA 94302, USA.

books are now in the Hindi language. The story is enhanced by the personal experiences of the facilitator, thus involving local people in local situations. The story is then given to the local radio station director to be presented (once a week) on the Doctor's Hour, or Health Hour, or a women's educational program. The text is later printed into pamphlet form. These pamphlets are taken to the village classes and used as "text books". They are then given free of cost to the persons in the local community to be used as references and copies are left at the "centers". One copy of each of Werner's books is given to the village centers too. Readings from these books take place at the beginning of each study session. The "teacher" (usually a participant of one of the educational programs mentioned earlier) explains the text in relationship with the pamphlet story. Discussions are held.

Program presenters and volunteers are asked to write own articles about mental handicap, special education, case histories, and related subjects. These contributions are then submitted to local newspapers, magazines, and other local publications. A two-years illustrated storyboard collection (comic strips), called The Melting Pot, has been published regularly in a local (nationwide) magazine. The once-a-week illustrated story focuses upon educational messages related to physical and mental disabilities. (The comic strip will be published soon in several other Asian countries.)

It is hoped that many of the people in the District will hear the radio programs. Some people will receive and read the pamphlets. Others living in the villages will have the text books. Some people will read the newspapers, and/or the comic strips. And the village people will hear the lectures and assist in local pedagogic units. Parents are expected to service severely handicapped children who cannot leave their homes.

Parents are the "core" group once again - the primary educators. Home and communities are the "basic classrooms". The program is assimilated into local traditions and educational structures. One person only, the facilitator, coordinates the entire program. Costs are very minimal, and are covered by donations.

Asia has other examples of informational-based programs involving radio programs, television programs, etc. In China, our educational programs have been video-taped in their entirety, and then shown on the national educational channel as part of the government's social education efforts. Asia presents a challenge to willing people to use creativity, to experiment in cultural forms to educate people in ways and means to care for persons with special educational needs.

CURTAIN CALL

There are significant indications that most Asian nations are establishing an institutional or structured approach to the education and care of persons who are intellectually handicapped. These efforts are in the early stages in some countries (the existence of one facility or of one organization only); in other countries, which are more economically stabilized, institutions and advocacy groups abound. Regardless, a "mass problem" requires a "mass manpower" response.

Good intentions and plans, however, are blocked at times because of the lack of proper funding, the improper use of facilities (resulting in abuse and dehumanizing conditions), and by official bureaucracy. Confusion as to the purposes of education, of care, of rehabilitation, and of welfare does hamper the just cause of advocacy for persons with mental handicap. A few Asian countries are busy searching for ways and means to have mentally (and physically) handicapped persons become productive citizens, and contribute to the nations' economies. This pragmatic reasoning has led to a great stress being put on vocational education (sometimes to the detriment of education itself) in those countries.

There are more and more local associations and movements being formed by persons with mental handicap themselves, by parents, by non-government agencies, and by volunteer services in order to reach out to the unreached millions of people in Asia. There are expanding international exchanges concerning educational programs for persons with mental handicap. There is growing participation of persons with mental handicap themselves to express their aspirations at international and regional conferences (organized for example by the International League of Societies For Persons With Mental Handicap Conferences; the International Association For The Scientific Study of Mental Deficiency; the Asian Federation For the Mentally Retarded, etc.). There is an increase in exposure and informational visits to related groups in neighbouring countries. There is a functioning cooperative movement between national associations. "Labelling" barriers are slowly being broken. The monopoly, long-held by professionals, on the structure and directioning of work with people who have special needs, is coming to an end in a few countries. Many parents - the most talented and responsible natural teachers - are claiming their rights to teach and to care for their children. Persons with mental difficulties, as a group and individually, are organizing themselves in order to determine their own goals in life and their independent vocations.

There are some research programs being conducted in Asian countries to determine causes, prevalence and the impact of physical and mental disabilities on the nations. A limited number of countries here have enacted civil legislation defending, extending, and defining the rights of persons with mental handicap. These laws intend to localize the United Nations' declarations on the rights of persons who are mentally handicapped. Integration of persons with mental handicap into normal school classrooms has been introduced in several areas. However, some poorer nations still protest that: "We do not have enough room for normal students. So we cannot consider taking handicapped children into our present schools." There are also many places where normal school teachers openly and strongly oppose this mainstreaming process.

Asian countries have learned much about, and often imitated, the good and bad achievements from the West. Many places in the Orient are sharing their own good achievements and bad achievements with the West. Our experiences, however, have given us overwhelming certainty that all people partake equally in this one world; in one humanity, in one purpose. Nevertheless, an evident mutual respect is seen to be developing slowly among all people. Many Asians are working ardently for the education and care of persons with mental handicap. So are people in the West. "We" have been touched in our hearts at seeing the love "they" have for persons with intellectual handicaps; and "they" have been touched in their hearts at seeing "our" love for all people with special needs.

We - from the East and from the West - realize that our tears of joys and sorrows are the same. We - from the East and from the West - realize that our smiles at success and accomplishments are the same. It is in a solidarity of sharing and equality that the mass manpower movement can, indeed, do much for the many people in Asia who are in the world of shadows.

Jean Vanier, in his book Tears of Silence, gives light to our vision:

He who is
or has been
deeply hurt
has a RIGHT
to be sure
he is LOVED.
Love,
not just some passing moment
a glance however open
but some deeper compassion
radiating permanency.
Not some morbid curiosity
some gushing pity
incompetent naivete
the cry of burnt-out eyes
wounded bodies
addicted minds
cravings
can only be answered by some love
in which is felt a strange presence of the eternal
a hope
a new security ...

We see light and warmth of a living performance come to the Asian scene of education, of service, and of rehabilitation of persons with mental handicap. The stage is long readied. The curtain is rising on the world in the East. And a hope, a security is there that a deeper understanding and a greater efforts by those on the stage and by those in the audience are certain to bring success to the Asian worlds and their people, who strive so sincerely in their education and care of all normal persons, who happen to be "slow".

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The International League of Societies for Persons with Mental Handicap (ILSMH)

Founded in 1960 by representatives of societies of parents of mentally handicapped persons, friends and professionals in the field of mental retardation,the ILSMH is devoted to defending the rights and interests of mentally handicapped persons without regard to nationality,race or religion. The League addresses problems related to mental retardation: among them are prevention, diagnosis and early treatment, education and training, economic security, social welfare and integration, guardianship, interfamilial relations, due process of law and public education.

To achieve these objectives, the League, with the help of its member societies, organizes international symposia of experts, regional conferences and world congresses. The League publishes the results of these efforts, an international newsletter translated in four languages, and various pamphlets on topics of general interest. The League has consultative status with UNESCO, UNICEF, ILO, WHO, ECOSOC and the Council of Europe, and has official relations with the European Communities and other international organizations interested in handicapped persons.

Training of Persons Who Care for Persons with Mental Handicap

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International League of Societies for Persons with Mental Handicap
Ligue Internationale des Associations pour les Personnes Handicappées Mentales
Liga International de Asociaciones en favor de las Personas con Deficiencia Mental
Internationale Liga von Vereinigungen für Menschen mit geistiger Behinderung

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